MD STARnet

Muscular Dystrophy: Muscular dystrophy (MD) comprises a group of genetic disorders characterized by progressive muscle weakness. There are many forms of muscular dystrophy. Different kinds of muscular dystrophy have different genetic causes, affect people at different ages, and affect different muscles. This project will initially focus on childhood onset Duchenne muscular dystrophy (DMD) and Becker muscular dystrophy (BMD), or Duchenne/Becker muscular dystrophy (DBMD). DBMD is the most common muscular dystrophy in children, and affects males almost exclusively.

Muscular Dystrophy Surveillance Tracking and Research Network

Surveillance: The goal of this project is to identify all children with DBMD in defined geographic areas. Children will be identified by using information from different sources, such as clinic medical records and hospital records. Because we will continue to identify children with DBMD, systematically collect and analyze data, and report findings on an ongoing basis, this effort is considered to be a surveillance activity. As such, it will provide better estimates of the number of people with DBMD, which in turn will allow communities to identify resource needs and provide better services. In addition, by identifying males with milder forms of DBMD, researchers might be able to identify reasons why these males have milder forms.

Tracking: After children with DBMD are identified, public health scientists will collect information at regular intervals to keep track of each child's treatments and how he is doing medically. Families will also be invited to participate in interviews with public health representatives to gather information related to DBMD that is not found in the medical records.

Research: We will pool the data anonymously (without names) from the different sites to answer questions such as:

- How common is DBMD?
- Is it equally common in different racial and ethnic groups?
- What are the early signs and symptoms of DBMD?
- Do factors such as the type of care received or the type of mutation affect the progression of DBMD?
- What services are families receiving?
- Do different populations receive different care?

Network: CDC is working with Arizona, Colorado, Iowa and western New York state on this project.

Other CDC Activities: In addition to MD STARNet, CDC is working with several other research partners to collect information on families' service needs, look at health concerns of female carriers, and study issues related to potential newborn screening for DBMD.